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Experts Views on the Use of Mobile Devices to Support Patients with Mild Learning Disabilities During Clinical Consultations

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Abstract

Due to several factors including time and budget constraints, General Practitioners (GPs) are often under-trained on the communication needs of patients with learning disabilities (LDs). As such, they may find it difficult to extract accurate information from these patients. Digital technologies have the potential to alleviate communication barriers, yet their use in this context remains vastly unexplored. Hence, we conducted 2 focus groups with 12 experts in LDs to investigate how tablet applications may be used to promote the information exchange process between GPs and patients with mild LDs. The experts identified an initial set of design criteria for the future implementation of these technologies and were enthusiastic about the potential impact they may have on primary care. In addition, they also discussed a potential model for extracting medical information from this population, which focused on breaking the overall consultation down into smaller, less cognitively challenging segments.

Keywords:

Mobile Applications; Intellectual Disability; Primary Health Care

Introduction

People with learning disabilities (LDs) are more susceptible to a range of conditions and comorbidities [1] and therefore have a higher demand for healthcare services compared to that of the general population. Despite this, the standard of care being provided is often inadequate [1] and this has a detrimental impact on both the length and quality of their lives.

To determine the overall scale of the problem, researchers at the University of Bristol conducted an inquiry into the premature deaths of people with LDs [1]. They examined the cause of death of 247 patients with LDs across 5 primary care trusts in the South West of England and found that approximately 50% were avoidable. Of these deaths, 27.5% were directly amenable to better care and this suggests that such patients are being subjected to serious health inequalities.

Previous studies [1–5] have investigated the various barriers to providing primary and secondary care for people with LDs, some of which may contribute to the findings made by Heslop et al. [1]. This literature covers a span of 2 decades, and with a number of barriers appearing consistently throughout, it is clear that effective support for this population has not been identified. Some of these obstacles include: difficulties identifying and accessing appropriate services; under-trained staff on the health and communication needs of patients with LDs; inflexible procedures; and insufficient collation and use of health care data.

Central to many of the identified barriers is communication. In primary care, this is extremely problematic since Howells suggests that “the art of general practice lies in the ability to communicate with patients” [6].

Nevertheless, patients with LDs have a number of impairments that affect their ability to convey medical information [2,3,7,8]. In addition, General Practitioners (GPs) often lack the skills required to adjust their consultation methods to limit the effect these impairments may have on the appointment [3,5].

Consequently, the overall goal of our research is to investigate the use of Alternative and Augmentative Communication (AAC) applications to promote the exchange of information between GPs and patients with mild LDs. AAC technologies are used to enhance an individual with disabilities capacity to communicate by offering those who cannot speak a platform to convey their needs (alternative), or by supplementing the vocabulary of those who can (augmentative). This contrasts with traditional information applications, which often treat accessibility as an afterthought.

Throughout the paper, we will present the results of an exploratory study in which 12 experts discussed how tablet AAC applications can improve consultations involving patients with mild LDs. The requirements listed will assist in the future development of medical AAC applications that target the needs of these stakeholders.

Background

In this section, we define the term “mild learning disability” and introduce some of the impairments common to this population that may have an adverse effect on the consultation process. We then discuss the available guidelines on how to communicate effectively with patients who have LDs, before giving an overview on the current use of digital technologies to promote the health of these patients.

Mild Learning Disability Characteristics

An individual may be diagnosed with a learning disability if they satisfy the following 3 criteria: their intellectual functioning is impaired; their social functioning is impaired; and the aforementioned conditions occur before adulthood [9]. LDs typically manifest across a scale ranging from mild to severe; however, those with mild LDs are generally able to communicate their everyday needs but may struggle with more complex concepts such as describing symptoms. A number of impairments tend to coexist with LDs that affect an individual’s capacity to communicate their medical needs.

These include: cognitive impairments that affect vocabulary and sentence formulation skills, meaning the patient may not

possess the language required to accurately describe symptoms; reduced receptive skills that may affect their ability to understand the GP; limitations in their abstract thinking and long-term memory which may affect their ability to provide an accurate medical history; and a restricted knowledge of the human body, meaning they may not even recognise the presence of symptoms [2,3,7,8].

Guidelines in Consulting with Patients who have LDs

National and international guidelines e.g. [10] have been developed to assist medical professionals in conducting consultations with this population. Much of the advice regarding communication focuses on carrying out reasonable adjustments to cater to the individual needs of patients [10]. Some of the key recommendations include: extracting information directly from the patient; establishing the patient's preferred method of communication as early as possible e.g. by reviewing a clinical passport [11] if available; targeting a range of communication modalities based on the needs and preferences of the individual; and avoiding the use of medical jargon. GPs should also consider: utilizing gestures to emphasize communication; being vigilant for any additional information conveyed by the patient's body language; making sure the person has understood the information they have received; providing additional time for the patient to consider any information conveyed; and supplying information in advance of the consultation to help the patient prepare for the appointment.

Existing Health Applications for People with LDs

Researchers in the past have explored the use of digital technologies in a number of areas of health including: dentistry [12]; psychiatry [7]; and patient profiling [13]. Once again, this literature highlights the importance of exchanging information in a manner suited to the patient's individual needs. In particular, Menzies et al. recognized that the sole use of speech was not sufficient in conveying dental information to patients with cognitive disabilities [12]. Instead, they found that imagery/videos were particularly effective in describing the potential procedures to be carried out and the tools used within them. Furthermore, the professionals involved in this study requested features that assist in determining the patient's preferred method of communicating the terms "yes", "no" and "stop" – three aspects deemed crucial to their care. Prior et al's. study explored this functionality in further depth [13]. They developed a digital aid that extracts vital information from the patient (such as their communication needs, allergies etc.) prior to treatment. This information may then assist medical professionals in providing improved care, since they will be able to utilize the best practices when interacting with a patient. Bostrom & Eriksson investigated the possibility of providing healthcare data in advance of appointments [7]. They found that questionnaires could be successful in highlighting potential psychiatric conditions providing the information presented is accessible to stakeholders.

Methods

To determine the feasibility of embedding AAC applications in primary care, and to identify initial requirements that cater for the needs of patients with mild LDs, we conducted 2 focus groups with 12 experts in LDs (found in Table 1). We recruited experts in this study, as opposed to GPs, since they have extensive knowledge about the needs of people with LDs – a characteristic often not found in traditional medical professionals [5].

The LD nurses also understood the procedures involved in the consultation process, meaning the experts were better suited to identify how the proposed technology can support such patients. The set of features discussed will be expanded on during future studies that incorporate the views of both adults with mild LDs and GPs.

Table 1 – Expert Demographics

| Expert IDs | Profession | Sex |
|---------------|--|-------|
| 1.1, 1.2, 1.3 | Academics in the health and well-being of people with LDs. | F,F,F |
| 1.4 | Employee of an advocacy charity for people with LDs. Has mild LDs. | F |
| 1.5 | Employee of an advocacy charity for people with LDs. | F |
| 1.6 | Former LD nurse. Manager of a resource center for people with LDs. | F |
| 1.7 | Digital Inclusion Assistant. | M |
| 2.1, 2.3, 2.5 | Community LD nurses. | F,F,F |
| 2.2 | Employee of an advocacy charity. | F |
| 2.4 | Employment support officer | F |

The focus groups were designed to achieve 2 goals: (1) improve the accessibility of co-design techniques that may be employed within future workshops; and (2) identify an initial set of features for the development of the application. This paper will primarily focus on the results pertaining to goal 2. All 12 participants were required to complete the 4 activities shown in Figure 1 - the details of which have been described in the "Data Collection" subsection. These activities were identified during a review of previous literature that aimed to explore the use of co-design processes with participants who have LDs. They were selected to address 3 specific aspects of the proposed application: appropriate imagery to capture medical symptoms; its overall functionality; and the design of the interface including the layout of each screen.

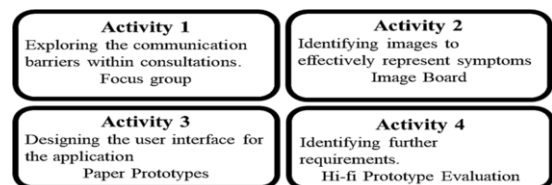


Figure 1 – The 4 Co-design Tasks Presented to the Experts

Invitations to participate in the study were issued (via email & telephone) to various charities, universities and hospitals throughout Scotland in May 2018. Seven experts from the city of Glasgow and 5 from Dundee consented to take part and formed focus groups 1 and 2 respectively. The focus groups were carried out in June 2018. Ethical approval to conduct this study was obtained from the Department of Computer and Information Sciences Ethics Committee at the University of Strathclyde.

Data Collection

The first task completed by the experts was a focus group that aimed to explore the primary barriers to effective health care for patients with LDs, as well as the potential use of digital technologies in mitigating these barriers.

The questions presented focused on the following 4 themes: (1) preparing for an appointment; (2) positive and negative encounters with GPs; (3) aptitude in using touch screen

technologies; and (4) how technology may be used to support the patient throughout the consultation.

Open-ended questions were primarily used to promote discussion and the session was conducted on a semi-structured basis to ensure the experts were able to raise, and expand upon, topics unforeseen by the authors [14].

The second task involved employing the image board methodology [15] to identify appropriate pictures to be included within the application. The experts were required to review images that depict common symptoms experienced by people with LDs and then separate these into one of two categories: those that accurately capture the condition; and those whose meaning is more obscure. A discussion then occurred as to why some images were more effective in capturing this information than others. Each symptom was portrayed using 3 separate styles of images - photorealistic, cartoon drawings, and simplistic black and white drawings to determine the style best suited to people with mild LDs. These styles were selected since they are often used in health-related resources for people with LDs.

The penultimate task consisted of a basic paper prototyping process. This involved placing/drawing elements onto a paper representation of a tablet based on the experts' views of the functionality and layout of each screen.

The fourth task involved the evaluation of a previously developed tablet application to try and discern the requirements that were not identified during task 3. This process was modelled around a "think-aloud" [16] session where the participants were required to complete 2 exercises and describe their reasons behind the actions being performed during real-time.

Data Analysis

The focus groups were recorded with participant consent and transcribed verbatim. The transcriptions were then subjected to a framework analysis to ensure a structured summary of the key features/requirements discussed was obtained. An initial thematic framework was developed by the first author based on the themes that emerged from a previous scoping review of the technologies used to support patients with mild LDs during clinical consultations.

The transcripts did not conform entirely to this framework and further codes were created to address this issue, at which point similar codes were grouped together to form overarching themes. The framework was reviewed by the second author and any discrepancies were resolved by the third author. The first author then tagged the transcriptions using the final framework and the relevant excerpts were transferred to their appropriate positions in the framework analysis table made available via the following doi: 10.15129/76f97730-a5fa-49da-973f-995373cee7ad. The requirements presented in the next section are based upon the main themes/sub-themes that emerged during this process.

Results

In this section, we present the key requirements identified by the experts. The quotes used to support these features are referred to using the participant ID listed in Table 1.

Simplifying the Consultation Process

The experts were of the opinion that the consultation process is often too complex for people with mild LDs.

Patients generally have to contemplate or provide information on aspects that are difficult to understand and must achieve this using methods that may be unsuited to their needs.

Consequently, the experts suggested developing technologies that help to break this process down into manageable sections, as discussed by participant 2.5:

"Could you not have something like that for the parts of the body - saying what part of the body the pain is in first of all? Once you've narrowed it down, have a different set of cards to say what type of pain is it? Is it hot pain? Does it [feel] cold? Is it sharp like a needle or something?"

The participants in focus group 2 also recognised that the application should explore conditions that do not involve pain: participant 2.5:

"I suppose the problem is if [you] start with body parts and then go on to what's wrong with that body part, general symptoms of tiredness [for example] wouldn't be [picked up]. Do you know what I mean cause they might just feel totally drained all the time."

In summary, the experts suggested a potential model that may be utilized by GPs to explore the health of patients with LDs, as shown in Figure 2.

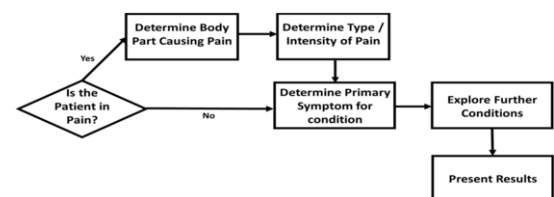


Figure 2 – Suggested Model for Diagnosing Patients with LDs

Utilizing Appropriate Modalities

The experts discussed two key strategies that may assist in promoting the accessibility of medical information, the first of which centres on the language used and the second focuses on the incorporation of images.

Comprehensible Language

Whilst describing appropriate language to be embedded within the application, the experts frequently cited common accessibility guidelines. This included: utilizing plain and simple language, along with short sentences that focus on solitary ideas; employing a minimum font size of 12; and offering the ability to playback textual information. In addition, the use of concrete examples was emphasized by participant 1.6 when describing particularly complex concepts. Finally, the experts in focus group 2 revealed that closed questions are most effective in extracting information from this population.

Identifiable Imagery

All experts throughout both focus groups emphasized the importance imagery may have in conveying medical information. Nevertheless, they were unable to agree upon the style of image that will be most effective in achieving this. For example, the participants in focus group 1 found that the more photorealistic images managed to capture the symptoms accurately, as described by participant 1.3:

"I thought this tired one was quite good it was quite realistic - better than the sort of drawing of someone lying in their bed. I suppose that's a bit more cartoony, I think I prefer the actual person."

In comparison, the experts in focus group 2 advocated for the use of the more simplistic black and white drawings, as discussed by participant 2.3:

"I prefer the egg head kind of ones 'cause they're not male or female. You know you might get a female with autism who's like that's not me 'cause [the picture is of a man]...And also,

less colour - just the black and white (colours) I think is more effective."

These excerpts suggest that a range of needs will have to be catered for by the images implemented within the application and this matches the views of participant 1.6:

"It's quite difficult because when you think of people, some will really connect with some of them [the pictures] and some individuals will connect with others."

Combining Modalities

In addition, the experts in focus group 1 revealed that the combination of text and images provided the most complete and accurate description of the symptoms presented as discussed by participant 1.4:

"You have headache at the bottom and I think if it didn't have headache at the bottom it would be quite confusing 'cause it could [mean something else]. So I think it's good with the headache heading."

Identifying Most Appropriate Communication Strategy

Participant 2.3 also discussed the benefits of using the application to identify the communication needs of the patient:

"My sister is a radiographer and sometimes there will be a little footnote somewhere [suggesting] some sort of learning disability and she's like 'okay that's good to know but I want [more information]. You know, avoid saying this or use this approach'".

This has the potential to increase communication significantly and matches the process described by both Menzies et al. [12] and Prior et al. [13].

Guiding the Patient

The experts in focus group 2 discussed two common scenarios that generate a heavy burden on healthcare services. Firstly, participant 2.4 suggested that some patients book medical appointments for the social experience as opposed to actually requiring treatment:

"So [sometimes] they use health professionals inappropriately. You know, they make appointments with the doctor and they don't have any symptoms, they just want to talk to somebody. The doctor won't find the symptom cause there's not one there."

The second involves patients prematurely booking appointments for conditions that have just occurred and will heal in due course, as discussed by participant 2.5:

"For some of our clients, I don't see any point in [them] going to the GP. Sometimes it's something that's just happened and we expect it to be like that so [they shouldn't] go to the doctor."

To overcome these issues, the experts discussed implementing a feature that makes use of the extracted information to suggest a course of action for the patient, as explained by participant 2.5:

"Whether you can have solutions at the end to say well how long have you had a headache for? Right, try [taking] paracetamol or try drinking some water or a lie down or something. You know go and tell your care worker or your family first of all, so it could almost be like a filter."

Consequently, the application could be used in the patient's home, before directing the individual to treatments out with primary care for minor ailments such as short-term headaches.

However, the app may also suggest that the individual contacts a medical professional, at which point the extracted information can be embedded in the consultation process.

Further Features

This subsection describes those features that were deemed to be important but do not fit into the previous 2 themes introduced.

In addition to presenting closed questions, participant 1.2 revealed that the amount of choice available should be limited, preferably to 2 options:

"I think as much as possible if you could have yes/no questions or like a tick and a cross to say is it painful [for example]. I think they might struggle if there's too many options."

The experts were also concerned about the user possessing the attentiveness required to complete the questionnaire, as discussed by participant 2.5:

"Even if they put down symptoms in different parts of the body and they gave up - if they take that to the GP, they could see some of things going on."

As such, they discussed the need to record the patient's progress to be completed at a later date or subsequently presented to the GP for review.

Discussion

Prior research has shown that digital technologies have the potential to increase the health of adults with LDs [7,12,13]. We add to this body of literature by highlighting the positive impact AAC applications may have within consultations involving this population. The experts were particularly enthusiastic about the technologies ability to support GPs in implementing many of the communication guidelines discussed in the "Background" section [10].

Previous research has explored extracting medical [7] or personal [11,13] information from the patient in advance of the appointment; however, the experts suggested that an application that combines both of these strategies should lead to optimal communication. Extracting medical information will enable practitioners to shape the questions to be presented, thus affording them more time to focus on aspects that may be crucial to a diagnosis. Furthermore, the patient may have more time to deliberate the questions being asked and subsequently construct an appropriate response. Obtaining personal information will enable the GP to utilize the strategies most suited to the patient's needs, which may ultimately increase their comprehension of the data being presented.

In accordance with the findings of previous literature [7,12,13,17,18], the experts highlighted the importance of combining images with accessible language to convey medical information. Nevertheless, they were unable to agree upon the style of image that captures this information best and instead revealed that a wide range of preferences must be catered for to meet the needs of people with mild LDs. Two strategies could be used to achieve this. First, several sets of images may be developed with the option to dynamically change between these sets e.g. when a user is unsure of the meaning conveyed by a particular image. However, this process may be cognitively challenging for people with LDs. As such, the second option involves the user completing an initial questionnaire that determines the most effective style of image to be embedded in the system, based on the individual's needs. Furthermore, the experts suggested that the application could assist in limiting the amount of unnecessary appointments attended by the patient.

This problem is also common throughout the general population, yet there is evidence to suggest that a higher percentage of people with LDs live with undiagnosed conditions e.g. [19]. Consequently, it is more important for these patients to seek medical care since more serious conditions may be the source of their current problem. The application can assist in this process by exploring all potential causes for the symptoms extracted, before suggesting a course of action.

A plethora of guidelines are available e.g. [10] to assist practitioners in conducting consultations with patients who have LDs, yet little research has been conducted into the specific questions to ask such patients. The experts discussed a potential model to achieve this by breaking down what is essentially a difficult process into more manageable parts. This process is shown in Figure 2 and consists of deducing whether the patient is pain; extracting the primary symptom causing their condition; and finally exploring any additional symptoms that may be present.

Conclusions

In this paper, we have presented one of the first studies to explore the potential use of tablet AAC applications to support patients with mild LDs during clinical consultations. Twelve experts in LDs participated in 2 focus groups throughout Scotland and subsequently identified a set of design criteria for the future development of such technologies. Developers will therefore be able to consider a variety of complex needs required by people with LDs and this criteria may be expanded on during future research with target stakeholders. In addition, this process has resulted in a potential model that may be utilized by GPs to extract symptoms from patients with mild LDs.

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